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ABSTRACT

This "feature issue" reports on consumer-controlled housing for persons with developmental disabilities, and explores housing and service options that empower individuals with disabilities to live their lives with independence, privacy, and freedom of choice. It includes an excerpt from the Association for Retarded Citizens position statement on residential living arrangements for persons with disabilities. Also contained in this issue are: "Your Place, or Mine?" (Robert Laux); "There's No Place Like Home" (Edward Skarnulis); "Creating Inclusive Communities: Profiles of Four Programs"; "A Home of Their Own: The Vision and the Reality"; "Seven Issues for Parents"; "Organizing To Develop Housing"; "Replacing the Continuum" (Derrick F. Dufresne); "A Provider's Guide to Survival" (Gerald Glomb); and "Resources for Financing Community Housing." Seven printed resources are described. (JDD)

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Your Place, or Mine?

by Robert Laux

Home. A place to hang your hat, call your castle, or find your heart. To me, home brings up thoughts of crackling fires, backyard chats over the fence, weekend projects, friends, neighbors, celebrations, Michelob, family, barbecues, and a place of solitude. To our homes we sometimes invite others and sometimes choose to be by ourselves. The choice is ours. That's what home is all about.

Audrey and Bob Lockwood with daughters Druanne (left) and Stacy outside their daughters' home.

For many people with developmental disabilities, home represents something decidedly different. Those remanded to group facilities may face bans on fireplaces, fences that hinder contact, weekends filled with shift staff, "paid friends", indifferent or even hostile neighbors, few things to celebrate, no "adult" beverages, absent families, staff who cook, and a world filled with 24 hours of habilitation. Our lifestyles and homes bear little resemblance to theirs.

A home shouldn't include a roommate, unless you want one. It shouldn't be disrupted by staff who come through your life in eight hour shifts. It shouldn't include forced group activities when you'd rather stay home and watch a ballgame. The homes and corresponding group living lifestyle we often create for citizens with disabilities are most reflective of a segregated housing alternative that none of us would find acceptable. Group living, as a preferrred way of life, is not common in our culture and few of us would even choose to live with our three best friends. Somehow, however, those responsible for planning appropriate, individualized services for citizens with disabilities perceive that this class of people is uniquely qualified to live in groups.

The allure of operational funding often plays a large role in the policymaker's choice of housing options deemed best suited for citizens with disabilities. A

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From the Editors:

Below is an excerpt from the Association for Retarded Citizens - U.S. position statement on residential living arrangements for persons with disabilities. That organization's statement sets forth the premise of this issue of IMPACT. The articles in this newsletter explore housing and service options that empower individuals with disabilities to live their lives with the independence, privacy, and freedom of choice that we all desire for ourselves. It is a beginning look at ways to redirect our resources to enable individuals with disabilities to live in a manner reflecting their own visions for their lives.

The Association for Retarded Citizens advocates for public policy changes and full funding to support the development of community-based residential programs for persons with mental retardation to grow, develop, and enjoy life. The ARC further believes that:

- All persons with mental retardation have a right to live in their local communities with nondisabled citizens.
- Community-based residential services for persons with mental retardation should be designed to meet the needs of the individuals.

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A report from the Research and Training Center on Community Living and the Institute on Community Integration at the University of Minnesota. Dedicated to improving community services and social supports for persons with developmental disabilities and their families.

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There's No Place Like Home

by Edward Skarnulis

"... be it ever so humble, there's no place like home."
-- from "Home Sweet Home," first act of the opera Clari, the Maid of Milan, Covent Garden, London, May 8, 1823.

Having a home of one's own is a life dream of people around the world. Home ownership has been a major element of our "American Dream" since this country began. It is associated with rites of passage to adulthood-- with emancipation from childhood-- and it conjures up images of security, stability, and wealth, however modest. Real estate has been the personal financial cornerstone for disparate types, everyone from the Rockefellers to Archie and Edith Bunker.

While figures on real estate values reveal the tangible economic benefits of such an investment (the average sale price of existing single family homes rose from $22,300 to $112,800 between 1968-88 according to the National Association of Realtors), they don't reflect the intangible rewards of having a place to call one's own. One need only listen to the words that are used by citizens with disabilities to describe the experience of moving from a "facility" or "residence" into their own homes to understand what a home is to us all. The words they use include: empowerment, choices, freedom, independence, pride, and mine.

Clearly housing for persons with disabilities has been big business, and yet it hasn't brought them any closer to homes of their own.

Increasingly, we hear talk about "valued futures" for children and adults with developmental disabilities, about a vision of what their world should/could be. What do we hear when we ask these individuals, their parents, their siblings, and others that know them well about their desired futures? We hear of special likes and dislikes, personal preferences, unique characteristics, individual differences. Seldom do these intensely personal visions of self or loved ones mesh at all with the service system's view that their disabilities make them part of a homogeneous group suited for congregate living. On what basis do we feel that their desires and needs are less unique than those of people living in the 60% of U.S. households that own their homes?

The housing needs of persons with developmental disabilities ideally ought to be met in a manner consistent with the presumption that the housing will be owned and/or controlled by the individuals with disabilities or their families. This may seem like a modest proposition, but it is truly revolutionary with regard to the status afforded persons with developmental disabilities. Control of one's housing and ownership of real property is power, not only over one's immediate environment, but also within the larger society. Just consider the comparative political influence of constituencies, such as elderly citizens who pay property taxes in communities, as opposed to other groups such as persons with developmental disabilities who are viewed as totally dependent on tax dollars for all aspects of daily life.

Clearly much money has been spent over the past 20 years for housing for persons with developmental disabilities. However, those expenditures have created real property wealth for others. In the early 1970s, most people with developmental disabilites had two living options: stay at home with their family (with little or no support), or move into a state or privately funded institution. Since creation of a Title XIX benefit for people with developmental disabilities, specifically Intermediate Care Facilities (for people with) Mental Retardation (ICFs/MR), public and private dollars have been used for a variety of residential services, ranging from large institutions to small group homes. However, the service provider (public, private-for-profit, or not-for-profit) was also the owner of the buildings in which people lived.

The growth of the ICF/MR program has been sizable. In FY 1977 the combined total federal expenditures for public and private large, congregate (16 or more beds) ICFs/MR and community service residences (smaller than 16 beds) was over 600 million dollars. Based on Minnesota statistics, about 14% or an estimated 85 million dollars was spent on property costs. By FY 1988, property related costs were nearly half a billion dollars. That means that between 1977 and 1988 federal Medicaid payments for property costs were probably in the neighborhood of three billion dollars. Add to this private, state, and local housing expenditures and these estimated property expenditures more than double. Clearly housing for persons with disabilities has been big business, and yet it hasn't brought them any closer to homes of their own.

Important changes have been taking place. Some programs now allow, to a limited extent, separation of services and buildings. Congress made Title XIX more flexible in the early 1980s with Home and Community Based Waiver Services (HCBS). The HCBS covered only services needed to support an individual in his/her own home; housing and food had to be provided separately, either in the individual's own home or in a residential setting, through state, local or personal funds (including Social Security cash assistance). Many persons with developmental disabilities and their parents found they could choose a home rather than being "placed" somewhere. Many people with developmental disabilities stayed with

their parents and received services. Some people with developmental disabilities stayed in the family home and the parents moved out, contracting with a provider for services and using HCBS to cover the service costs.

Another important step to providing homes for persons with disabilities was the 1986 Congressional authorization of tax credits for states to encourage private investors to help people with disabilities lease decent, affordable housing. Not only does the investor (which could be a group of family members) benefit from the income derived from the property and the increased value of the property, but also from reduced taxes applied as credits to their federal income tax payments.

Given the price that thousands of people with disabilities paid by living in such places, it seems just that the monies accruing from their sale be targeted to homes in the community.

Recent years have brought other creative, and sometimes ironic, efforts to secure homes for persons with developmental disabilities. For example, many once isolated public and private residential facilities were built on land that is now extremely valuable either because it has been absorbed by sprawling urban areas, or because it contains valuable natural or recreational resources. This makes alternative uses of the land financially desirable. To a few creative and foresightful planner/advocates, it has seemed that these properties, through their sale, can provide funds for homes for people with disabilities. The income can be converted to funding pools that are used as collateral to back low interest loans for down payments on individual or cooperative housing purchases. Given the price that thousands of people with disabilities paid by living in such places, it seems just that the monies accruing from their sale be targeted to homes in the community. Australians are doing this with St. Nicholas Hospital (Institution) in Melbourne, and advocates in England are proposing the same for Normansfield Hospital in Teddington.

In past years and still too frequently, professionals have viewed responding appropriately to the needs of persons with developmental disabilities as primarily a matter of matching an individual's characteristics with a finite set of available "models" of residential service. Thus, we have various types and sizes of congregate living such as group homes and "semi-independent living units" or staffed apartments. Interspersed among these models are often more specialized sub-categories like "behavior shaping units", "medically fragile units", or "elder housing". Placement in these models has been based on one or two characteristics held in common by the residents (e.g., medical/psychiatric diagnostic classification, IQ, age), presuming a fundamental homogeneity among them. While such presumptions have allowed for administrative convenience, they have generally ignored the most basic tenet of assisting people: human beings are unique and unrepeatable. Children and adults with disabilities are no less individually representative of the diversity that we all share.

Increasingly, service provider agencies will need to be structured and committed to practices that balance the need for tailor-made living arrangements based on the person's world-- his/her family, friends, co-workers, neighbors, community, and culture -- with the need for support of widely dispersed homes. To borrow a definition from Rockwell International Corporation, we need to find balance in "stability based on planned diversity." We will have to recognize that there are no easy blueprints for people's lives, whether or not they come "categorized". Planners of those systems will need to take a lesson from the landscape contractors who don't pour sidewalks until they've had time to see where natural paths are worn. Future systems of residential services will eventually be the product of one-at-a-time creation of individual places to live.

The movement toward real homes has an elegant simplicity, but still faces many challenges. It is constrained by existing federal regulations, particularly under Title XIX of Medicaid, which continues to promote out-of-home congregate residences. Repeated attempts at Medicaid reform, which would allow the kind of flexibility needed to support people in their own homes, have not yet been successful whether because of a projected increase in federal expenditures, powerful interests maintaining the current orientation, or both. But there may be a more favorable climate approaching. The possibility of a "peace dividend" from Eastern Europe demilitarization, HUD Director Jack Kemp's support for empowerment of the urban poor through home ownership, and the growing respect for the rights of people with disabilities, are among the factors that may bring about the needed support service reform for people with disabilities seeking their own homes.

The struggle to gain control of one's home is something of a brave new world for people with disabilities. Most of the existing players are conditioned to accept the way things have been, and ground rules for the new concepts are still evolving. Governmental entities will often feel uncomfortable with the prospect of turning over resources and authority to the recipients of public funds, and will want safeguards for their use. Some service providers who have benefitted from real estate investments will not be keen to redirect their focus away from bricks and mortar to services. Consumer controlled housing is another stage in the evolution of rights and respect for persons with developmental disabilities. And this stage acknowledges that not only should the basic rights of persons with developmental disabilities be assumed to be the same as their fellow citizens, but so too should be their dreams and aspirations.

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Creating Inclusive Communities: Profiles of Four Programs

"A true community has no walls. To be included in a community requires knowledge and information. These two factors are critical in the lives of individuals with disabilities and their families. Lack of knowledge about supports that promote independence, productivity and inclusion means, fundamentally, that the dreams of individuals and families are limited."*

In a small town in southeastern Ohio, five adults with mental retardation are living their lives differently than many other adults with disabilities. They are not living in institutional or group home settings. They are not living in their parents' homes either. They are living in homes of their own choice, with roommates of their own choosing. They help select the staff that assist them in their daily activities. They decide the routine of their days and personally plan their leisure activities. This creative option in housing for people with developmental disabilities is made possible through the Ohio Department of Mental Retardation and Developmental Disabilities' **Family Consortium Project**.

Ohio's Family Consortium Project, unique in the nation, is a family-developed, family-centered, and family-driven program. The parents, relatives, friends, and persons with disabilities form consortia that serve as the administrative bodies that manage certified homes in which people with developmentally disabling conditions reside. Each consortium can include up to five persons with developmental disabilities and their family members/friends, with a maximum of four living in each home. One consortium may administer more than one home, as long as the total does not exceed five individuals with disabilities. Consortium members are responsible for selecting and carrying out personnel functions and overseeing programming of the home. The County Board of Mental Retardation and Developmental Disabilities provides monitoring, case management, and day program services for the residents with disabilities.

The structure of the program allows for several housing options. The individuals may purchase a home themselves with the assistance of family/or other citizens of the community who wish to pursue a financial investment. Parents may purchase a home and rent to their sons/daughters. Or, they may rent from a landlord.

The state funds supporting this project reimburse the consortium for the direct services of the staff. Other operating costs are absorbed by the consortium and could include buying/leasing/renting a home, as well as purchasing insurance, food, and furnishings.

Because the consortium homes are defined as "an extension of the family home," statutory regulations that ordinarily govern group homes are not applicable. The homes are certified by the County Board of Mental Retardation and Developmental Disabilities based on state guidelines and rules, and zoning and licensing requirements do not apply.

Some advantages of the consortium approach include:

- It allows parents to continue to play an active role in caring for their child's emotional, educational, and physical needs.
- It allows participants to select their own roommates and home location.
- It allows consortia to decide the amount to pay staff and the benefit package.
- It maximizes state and local funds, augmenting them with resources from the local community and the family of the member with a disability.
- It allows participants to stay in their home communities.

The consortium is not meant to meet everyone's needs. It is intended for families who have the desire to utilize a living situation for their son or daughter that maintains the family as an integral unit while allowing the individual to grow and gain needed autonomy and independence.

In Brookline, Massachusetts, **Specialized Housing Inc.**, is another consortium that is providing creative options for 42 adults with developmental disabilities. Begun in 1982 as an effort to promote community integration and inclusion through home ownership, the consortium currently provides the catalyst for individual ownership of 42 condominiums in Brookline, with 10 more units scheduled to open soon in Providence, Rhode Island. The project seeks to free individuals from the control of landlords, agencies, and public policy.

The condominiums are all in converted Victorian style homes. They are located in urban areas that offer convenience to shopping and public transportation. Downtown Boston is a twenty minute bus ride away from the existing units. Each condominium offers a combination of private and shared communal space (editors' note: this concept in housing could also be applied without the need for a

*** From *"The Heart of Community is Inclusion..."*, the 1990 Annual Report of the Minnesota Governor's Planning Council on Developmental Disabilities.**

communal, congregate approach). Trained staff are available around the clock to provide assistance if necessary, and the owners participate in staff selection. Housing is the primary service that residents purchase, and they receive help in managing it themselves with the continued operation administered by a management corporation.

Financially and legally, the development is like any other community condominium unit. Of particular note is that only private funds have been used for initial development and ongoing service support, with the exception of one household that has received state rental assistance administered through the local housing authority. Many of the individuals living in the condominiums have purchased them with support from their families, enabling them to buy the units outright. Others have made their own personal financial arrangements using bank mortgages. Owners pay real estate taxes to the town. This arrangement not only offers a secure and possibly permanent residence for the owners, it also offers the financial opportunity for income tax deductions and the equity of home ownership.

"Cross-collateralization of assets." That is the business term used to describe the strategy employed in 1987 by **Hammer Residences, Inc**., of Wayzata, Minnesota, when its board of directors decided to establish real homes for the remaining 46 adults living in their on-campus buildings. In a nutshell, cross-collateralization of assets means leveraging the value of existing assets -- in this case the land, buildings, and contents already owned by the corporation -- in order to obtain the necessary money to purchase other real estate. Today all former residents are living in the community, with support provided by the same skilled and dedicated staff members who once served them in the larger facility.

When Hammer School was founded in 1923 it was a welcome alternative to the state institutions. Parents were able to keep their sons and daughters close to home in the Twin Cities, visit them, and maintain contact. The program became well known nationally and internationally. It was a self-contained, caring community of paid staff, a parent-majority board of directors, and children and adults with mental retardation. Eventually the organization expanded beyond the campus dormitories, developing three group homes for six people, supervised apartments that housed a total of nine adults, and two homes serving three people each.

The tradition of single minded devotion to citizens with disabilities moved the leadership of the board to conclude that if integrated community living was good for the people living in the apartments and houses sponsored by the agency, then that same opportunity for a more normal life needed to be made available to the 46 people remaining in the larger dormitories. With the board's guidance, the executive director was instructed to begin analyzing what could be done to provide real homes for everyone, and how to pay for them. What became apparent was that the property on which the main buildings were located had become very valuable over the years; it was a valuable "island" surrounded by various commercial properties. Appraisals indicated it could be worth as much as $3 million. This clearly suggested that there should be no problem with using the real estate as collateral for banks or savings and loan companies, which in turn could be used to obtain loans for the down payment for each of the homes serving Hammer residents. The four bedroom homes were estimated to cost approximately $115,000-$130,000 apiece, and would require a down payment of 20%. The depreciation of buildings and furnishings would be billed against the per diem rate normally charged by a service provider, and paid for through normal home and community based waiver mechanisms.

Thus far, "the juice seems well worth the squeeze." Every day a new success story appears. A parent who lives in California and hasn't been able to visit for a number of years came to where his son lived. With no small amount of pride, the son said: "Where you staying, Dad? Don't have a room? Why not stay here in my home?" Other parents have commented on how comfortable it is to visit a regular home, and how much easier it is to get a sense of what's really happening in their daughter's or son's lives.

It's not Camelot of course, anymore than life is for the rest of society. Transportation is a challenge. If only one staff person is on duty at a residence, it may not be possible for each person with a disability to choose what s/he wants to do or where to go. Sometimes reimbursements for staff auto expenses such as increased insurance rates, are disallowed by Medicaid auditors on the grounds that staff aren't hired to drive, that it isn't "habilitation." And, of course, the challenge of training or retraining staff is ongoing.

One final note. It was hoped that at some point a corporate structure could be fashioned that would allow the people served by Hammer Residence, Inc. to become the owners of their homes through a housing cooperative, with each person purchasing a share for one dollar. In part because of so many competing priorities, that hasn't happened yet, but continues to be a hope of the agency's board and administrators.

Prairie Housing Cooperative in Winnipeg, Manitoba, began in 1982 to ensure that individuals with developmental disabilities would have opportunities for affordable housing, supportive personal relationships with friends and neighbors, and control and ownership of their own housing arrangements. The cooperative works by creating small neighboring groups of individuals or families dispersed throughout Winnipeg in duplexes, townhouses, or clusters of single family dwellings. Each grouping is designed to

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include and support one or more members who have developmental special needs, or one or two families with a child who has a handicapping condition.

Currently there are eight clusters of housing units in Winnipeg that involve approximately 85 people. They include one 28-suite apartment complex in a renovated downtown warehouse, one triplex, and six housing clusters containing two to four units per cluster.

Members of the cooperative include individuals and families who live (or plan to live) in units of housing owned by it. All members of the cooperative share in its design, administration, and support. They elect a board of directors that is responsible to implement the general aims of the cooperative through various committees, and each member has the opportunity to make significant contributions by participating in the working committees.

The cooperative is not just housing. It is designed to create networks of responsible neighboring relationships that include members with developmental special needs and emerging abilities. Ideally, the relationships include involvement in the social life of the family and community, acceptance, friendship, and mutual assistance. The relationships are chosen and voluntary, and are not intended to take the place of the formal supports that some members may need from time to time. A wide range of options for personal assistance are possible for members, ranging from the purely voluntary neighboring relationships to arrangements in which non-handicapped assistants share housing with members who need more extensive supports.

The cooperative is incorporated on a share capital basis, meaning that members contribute to the capital base through the purchase of common shares. Becoming a member involves purchasing a single share at a nominal cost (around $10.00). This entitles the member to a voice in the cooperative's operation. Resident members may be asked (and assisted) to purchase additional shares. The investment is a deposit that is held by the cooperative for the time that the member resides in the housing, and is refunded when s/he leaves, if financial obligations to the cooperative have been met.

Some of the important characteristics and benefits of the cooperative are the following:

- The cooperative belongs to all the people who use its services, and control rests equally with all members.
- It ensures that members who have handicapping conditions will have full voting rights and a powerful valued role in the design, governance and operation of the cooperative.
- It creates natural opportunities for interactions between citizens with and without handicaps, including opportunities for working together.
- It may become a vehicle for arranging the additional personal supports that some members may require.
- It creates continuity of place and relationships, and a sense of security. Even though individual members may leave from time to time, there remains a strong circle of friends and supportive neighbors.

Each of the housing options described here is an example of cooperation between individuals, families, and traditional service providers. Each has grown out of a desire and commitment to maximize creative housing opportunities for individuals historically denied ownership and/or control of their own homes. These ideas are certainly not new. They do, however, require making a commitment to each individual's personal situation with supports that allow for the maximum retention of independence and, thus, growth, involvement, and inclusion in the community.

For further information on the options profiled in this article, contact the following:

• ***Ohio's Family Consortium Project***: Ms. Vicki Grosh, Special Programs Coordinator, Ohio Department of Mental Retardation and Developmental Disabilities, Room 1250, 30 E. Broad Street, Columbus, OH 432266-0415.

• ***Specialized Housing, Inc.:*** Ms. Margot Wizansky, Specialized Housing, Inc., 12 Lincoln Rd., Brookline, MA 02146.

• ***Hammer Residence:*** Mr. Roger Dineen, Executive Director, Hammer Residence, 1909 E. Wayzata Blvd., Wayzata, MN 55391.

• ***Prairie Housing Cooperative***: Mr. Rudy Braun, Manager, Prairie Housing Cooperative, Ltd., 100-113 Market Ave., Winnipeg, Manitoba R38 0P5

The following individuals contributed to this article: David Hancox, Director of the Minnesota office of the World Institute on Disability; Vicki Grosh, Special Programs Coordinator, Ohio Department of Mental Retardation and Developmental Disabilities; Ed Skarnulis, researcher, Minnesota Department of Human Services; Margot and David Wizansky, founders and developers of Specialized Housing, Inc.; and Rudy Braun, Manager, Prairie Housing Cooperative.

A Home of Their Own: the Vision and the Reality

All good parents have a vision for their children's future that includes the eventual building of a life of their own as adults independent of their mother and/or father. That vision sometimes has to be modified if a son or daughter has severe disabilities. In 1980, Audrey and Bob Lockwood of Minneapolis latched onto the idea that their two daughters could live in a real home of their own, independent of their parents, even though both women have severe mental retardation and physical disabilities. The process of making that idea a reality took the next five years.

Though the leisure activities of Stacy (pictured here) and Druanne are presently similar to those found in group homes (such as riding exercycles and assembling puzzles), Audrey and Bob are working with their daughters to increase their involvement in community social/leisure programs.

Stacy and Druanne Lockwood once shared a five bedroom home with their parents. As the women entered their early 20's, Audrey and Bob thought that the house would be a perfect place for their daughters to live with other women their own age. In 1984, after encountering difficulty in implementing their plan due to changes in the law governing group homes, the Lockwoods were ready to give up on the idea. Their housing concept was categorized as a group home by the state, and a hold on funds to create such housing was in effect.

Then in 1985, Medicaid Home and Community Based ("Waiver") Services came into the picture in Minnesota. Waiver services made it possible for the plan to be put into action by making available funding for staff to come into private homes and assist families. Interviews were conducted with various management companies, and one was selected. The director of the management company became a foster parent to the women to fulfill requirements for the home's existence. Roommates were found among Stacy and Druanne's coworkers at a developmental achievement center. And so, in the fall of 1985, Audrey and Bob moved out of the home turning it over to their daughters, two roommates, live-in staff, and the management company.

During the first two years of the arrangement it was difficult getting the household to stabilize because staff turnover was high. That has slowed, and the newest staff member was hired almost three years ago. Three female staff live

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Seven Issues for Parents

Listed below are seven areas of concern for parents to consider when leasing a house to a provider that will staff and supervise the home:

• **Selection of housemates**: How should this be done? Whenever you have congregate residences, there has to be some give and take. People have to have the patience and willingness to accept the idiosyncracies of others. Everyone needs to understand that. But, people living together also have to be compatible. It's naive to believe that you can force people to learn to live with each other.

If the consumer is unable to make decisions about a housemate and if the house is to be owned by the consumer's parents, they need to have a sizable say in who is going to live with their son or daughter. Under no circumstances should they be forced to accept people because of some whim of either the provider or the county. The property may involve a very sizable investment by the parents. They carry the liability of the place. They need to be able to say who's going to live there. But they may have to adjust if they can't be accommodated and if the only alternative is not having anyone else living there to share the cost.

• **Whose house is it:** If two to four people with disabilities live in the house and one doesn't work out, who decides who leaves? Ultimately, the person who owns the house probably has a bigger vote than the other people. Obviously, this is a disadvantage if you're placing your son or daughter in a residence owned by somebody else. If one person is "more equal" than others, what are the plans and agreements to assure that there is no exploitation of a nonowner, especially a housemate with no family?

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Organizing to Develop Housing

Many efforts to secure homes for individuals with disabilities involve groups of families, advocacy organizations, or nonprofit organizations as sponsors of the housing. There are several initial considerations potential sponsors of housing should address when deciding to undertake such a project. These include issues related to performing a needs assessment; the legal ownership structure of a project; and establishing links among advocacy organizations, consumers, private sector builders/developers, government agencies, and the community.

Needs Assessment

A needs assessment should be the first step taken by potential sponsors of affordable housing for persons with disabilities. The sponsors may choose to use existing housing needs survey instruments, such as **A User's Guide to Needs Assessment in Community Residential Rehabilitation,** or **Assessing Housing Needs for Persons with Disabilities: A Guide and Resource Book***. Or, they may choose to develop their own data collection system. A housing market consultant can often assist the sponsor in making this determination. A needs assessment involves the following steps:

• **Identifying the target population**. Parent, advocacy or other non-profit organizations frequently represent a specific group of persons with disabilities and may already have identified the people they intend to house in the community. They usually have a network through which additional potential members of the target population can be identified. Builders or non-profit housing developers, on the other hand, may have only a broad goal such as "providing a greater percentage of housing units for persons with disabilities." In such cases, local advocacy groups, such as Independent Living Centers, the Association for Retarded Citizens, the United Cerebral Palsy Association, and others, can often assist builders/developers in identifying the target populations with special housing needs, the best strategies for meeting those needs, and the most effective approaches to marketing the housing to those populations.

• **Determining housing and service needs.** Determining the needs of a specific target population includes examining the following: affordability criteria based on income typically available for rent or mortgage payments; level of support services required and the availability of those supports in the community if not provided by the sponsor; architectural modifications needed to enhance access and facilitate independent living; and type of housing that will best meet the needs of targeted residents. The focus of needs assessment in this case is on determining the least restrictive setting in which each individual's need for support can be met, with the goal of providing housing that enhances the community integration of each resident.

• **Assessing how housing needs are currently met.** Potential sponsors should identify community-based housing that currently meets the needs of the target population. In doing so, sponsors can benefit from the experience of others in identifying what works for specific individuals and target markets.

• **Determining how to address unmet needs.** Local advocacy groups can frequently provide prospective sponsors with useful information on housing and service needs associated with different target group characteristics. Having determined what needs of the target population are currently met and what needs are not, sponsors will often discover several alternative courses they can pursue. One primary consideration for sponsors should be the appropriateness of the planned housing to meet the continuing needs of that population. Two areas of importance in ensuring the long-term usefulness of a project are trends in delivery of services and the degree to which a project promotes integration of people with disabilities into the community.

• **Assessing changes in the delivery of support services.** The movement of persons with more severe disabilities from institutions and other congregate settings into typical housing in the community is leading to a reevaluation of support services and of the types of settings in which specific service needs can best be provided. As service providers continue to redefine individual service needs in terms of the support, permitting more typical lifestyles and more independence for individuals with disabilities, integrated housing will be in greater demand. Those who sponsor housing should determine whether the proposed housing is likely to continue to be not only an appropriate residential setting, but also a sound investment. In several states across the country, housing providers and service delivery agencies have been confronted with the difficulty of divesting themselves of properties no longer

***A User's Guide to Needs Assessment in Community Residential Rehabilitation*, Ridgeway and Carling. Available from the Center for Change through Housing, University of Vermont, Department of Psychology, John Dewey Hall, Suite 101, Burlington, VT 05405. *Assessing Housing Needs for Persons with Disabilities: A Guide and Resource Book*, Human Services Research Institute. Available from HUD User, P.O. Box 6091, Rockville, MD 20850. Publication #4030.**

used to house persons with disabilities. This could have been avoided had these agencies purchased, or assisted families or individuals with disabilities to purchase, typical neighborhood housing.

• **Assessing the potential for community integration.** The need to provide access to the community's natural support systems was acknowledged in 1974 at the first National Conference on Housing and the Handicapped. The guidelines formulated at that conference for planning and developing housing for people with disabilities still apply: 1) housing should be conventional in appearance; 2) specialized housing should congregate no more individuals with disabilities than can be absorbed into a neighborhood or community; and 3) housing should be located near the hub of the community to provide access. Then, as now, it's recognized that the important feature of housing is the degree to which it promotes integration into the community.

•**Assessing a sponsor's needs, objectives and capabilities.** When a non-profit group takes the lead in initiating a housing project, it should examine its own needs and objectives with respect to property ownership, the level of financial resources the group is able to contribute or raise for the project, and its development expertise.

Property ownership can ensure a permanent supply of housing. It generally also places the burden of financing, managing, and maintaining the property on the owner. Any sponsor considering the development of housing must determine the extent to which it is willing to become involved in property ownership as a facet of its operation. Long-term property leases may, in some instances, be more appropriate for some sponsors than ownership.

Access to equity and mortgage financing is necessary, both to acquire existing properties and to develop new properties. Structuring both debt and equity financing for a project enables a sponsor to act independently as a developer/sponsor/owner of the property. If equity must be raised from a source outside of the sponsoring organization, then ownership of the property will be divided between the equity source and the sponsor/developer.

The type of project undertaken will determine the level of development expertise required of a sponsoring entity. New construction or substantial rehabilitation of a property requires greater expertise than does acquisition of an existing property in move-in condition. For more complex projects, it is advisable for a sponsor with limited real estate experience to enter into a joint venture with a private sector developer or non-profit housing development organization. In such cases, ownership of the property would generally be divided equitably among the parties involved (including the equity provider) in real estate investment entity. Alternatively, the party providing the development expertise could be compensated on an up-front fee basis and deliver a completed or turnkey project to the sponsor.

Determining the Legal Structure

Once the needs assessment has taken place, the structure of the sponsoring entity should be addressed. There are three basic types of real estate investment entities:

• **Limited or general partnerships**. Partnerships are a common form of business organization for real estate acquisition and development. Partnerships, whether general or limited, are essentially tax conduits; taxable gain and loss of the project are passed through directly to individual partners. Partnerships have the advantages of informality and flexibility. The major disadvantage of a general partnership is the unlimited liability of the partners. A limited partnership, on the other hand, affords partners the tax advantages of a partnership, with the personal liability limitation offered by incorporation.

• **Corporations**. Corporations are taxable entities separate from their shareholders and report profit and loss separately. Because a double tax is imposed on project profits, once at the corporate level and once at the shareholder level when income is distributed as dividends, corporate entities often do not own real estate directly. The advantage of a corporation is a limitation on personal liability.

• **Subchapter S Corporations**. S corporations have the separate legal existence of corporations but are treated for tax purposes essentially as partnerships, with project gains and losses passed directly to shareholders.

Frequently, no single group or entity possesses the expertise to handle all aspects of a development project. In these instances, a joint venture may be appropriate. A joint venture is an association bringing together two or more parties to act as sponsor of a specific development project. The joint venture may be structured as any one of the three investment entities listed above. Tax and legal liability considerations are generally the primary factors in determining the most appropriate structure of the sponsoring entity. Because complex issues are involved, sponsors should seek legal counsel when structuring the development/ownership entity.

Establishing Linkages

Identifying and assembling a development team with complementary skills and interests is a primary consideration in organizing to develop housing for persons with disabilities. Individual consumers with disabilities often lack the resources or experience to increase their housing opportunities. Efforts of inexperienced sponsors are often

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Replacing the Continuum

by Derrick F. Dufresne

As we enter the 1990s, our focus should be on finding a place to call home for every person with disabilities. And when the word "every" is used, it includes people needing ventilators, people presenting severe behavioral difficulties, people without speech, and so on. The degree of disability should have no relationship to the right of every person with disabilities to have a place to call home.

Historically, for persons with developmental disabilities, where they lived determined the level of support they were to receive and the dollars spent on their behalf. Individuals with special needs, behavioral difficulties, or the label "medically fragile", have been relegated to life in *facilities* where they are supposed to receive intensive and costly supports. People who are most capable, have the most skills, and pose the least amount of difficulty, get to live in *homes*, where they are expected to require few supports and a low investment.

Group homes, ICF-MRs, and other congregate living settings are an idea whose time has come and gone.

This thinking, called a *continuum* model, has set up a caste system of services. The model holds that people need to learn a certain set of skills in one setting to progress to another setting, resulting in creation of a series of facilities all of which have a different purpose. Each time a new diagnosis or a group of people in need presents itself, a new facility is developed. The highest goal is independence for the few, the proud, and the brave who can wade through the system. The more disabled people are, the more skills they lack, or the more difficulties they present, the further away they are from ever having a real home.

I have heard comments made about congregate care facilities such as, "She feels like that's her home," or "We even have numbers on the individual units and she has all of her personal belongings here." I can't help but wonder in those particular situations if a person with disabilities and his/her family would still choose a facility if they knew that other options existed.

What then can replace the continuum? An array of supports can be provided to a person with disabilities, despite their past failures or inabilities to "make it" in the community. Fundamental to this way of thinking is the separation of housing and services (supports). This concept, often called "supported housing", says that no matter where an individual lives, an equal amount of services or supports can be brought to him/her. Therefore, anything that can be provided in a state institution can be provided in a condominium. Anything that can be provided in an ICF-MR can be provided in a duplex. Anything that can be provided in a group home can be provided in an apartment. This includes 24 hour live-in staff, visiting nurses, therapies, and other interventions that have typically been provided only in facilities. In order for this philosophy to be implemented, previously held beliefs involving the intermingling of supports and where you live must be re-examined. This includes the recognition that while supported living is better, it is not necessarily cheaper. Some individuals will require an intensity of support that may meet or exceed the costs of some institutional care.

In supported housing, flexible supports are provided to an individual based not only on strengths and needs, but also on individual wants. Thus, where the individual lives, with whom s/he lives, and the configuration of supports, are not predetermined. One does not put a spade in the ground, develop a "facility", and then find out who is going to live there. In fact, in supported housing, the physical housing is one of the last things that is addressed.

I am certainly aware of the arguments that start with, "This is great, but it won't work for my son . He's too disabled." Or, "We tried Judy in the community once and it just didn't work." It is perfectly understandable why parents and even some providers currently believe that there are certain individuals that could never make it in an apartment, duplex, condominium, or small single family home. This belief in many cases is rooted in the continuum which holds that only people who are independent can live in a place called home.

Research and experience in recent years have caused a complete re-examination of the continuum. The best attempts of individuals working in congregate settings to teach "readiness" or community living skills may have limited success when the residents have difficulty generalizing skills between different settings, and when they're expected to learn new skills and behaviors while surrounded by others with behavioral difficulties and intensive needs. This leaves behind in many facilities a group called the "residual population" whose needs are so great they are rarely, if ever, referred for community placement. Individuals who do learn and grow are "rewarded" by a move to another facility, leaving behind their neighborhood, friends, and comfortable surroundings. Today, there are better options available and we we must pursue them.

Group homes, ICF-MR's, and other congregate living settings are an idea whose time has come and gone. Yet many individuals with severe disabilities still live in facilities. In this new decade, let us meet the challenge of enabling each of our citizens to have a place to call home.

Derrick F. Dufresne is President of Community Resource Associates, 736 Crab Thicket Drive, St. Louis, MO 63131.

A Provider's Guide to Survival

by Gerald Glomb

Providers of residential services to persons with developmental disabilities typically have created and managed the environments in which their services were delivered. This may have produced management efficiencies, but it relegated the people receiving services to the status of guests in their own homes. As the service system has evolved to become more responsive to the wishes of the people receiving its services, control over housing is shifting from service providers to clients. We have seen the gradual development of an array of living options that are becoming more and more the homes of their residents and less those of a provider. Working in these changing environments has convinced us that new opportunities as well as challenges await service providers.

What we seem to be seeing more frequently is the application of many of the principles of the evolving consumer movement to residential services. This promises to benefit the people who receive those services. Agencies that are to be successful in responding to these anticipated changes will need to assess the way in which they go about their work. Without a crystal ball one cannot say with certainty what changes will be required, but our experience offers some suggestions.

• **Providers will need to know, understand, and accept the values, lifestyle preferences and expectations of the persons receiving their services**. Stew Leonard, one of INC. Magazine's entrepreneurs of the year for 1990, has as his oft-quoted business credo: "Rule #1 - The customer is always right. Rule #2 - If the customer is ever wrong, refer to Rule #1." The client in his or her own home is a more savvy and demanding consumer. Agencies that are to be successful will need to adopt a strong consumer orientation. They will resist imposing their own standards or hiding behind organizational policies. Rather, they will focus their energy on meeting the expectations of their customers, for without them their organizations cease to exist.

• **Providers will need to become adept at reconciling the expectations of direct consumers with those of indirect consumers**. Parents, siblings, case managers and licensors may want outcomes from a service that are different from or even conflict with those desired by the person receiving the services. Indirect consumers tend to be more concerned with the meeting of standards while the client is more likely to be concerned with personal preferences and quality of life. More than ever, understanding the needs of the various consumer constituencies and being able to arrive at an aggregate set of expectations that are not in conflict will become a determinant of success.

• **Providers will need to appreciate that they are by nature an intrusion and will need to be creative in finding ways to make their services as convenient as possible**. Simply by being in someone's home we invade their privacy. The personal nature of the services we offer heightens this sense of intrusion as we are often privy to very personal aspects of people's lives. The successful agency will place great emphasis on providing training and developing service methods that help staff go about their work in a minimally disruptive and intrusive manner.

• **Providers will need to devise more ingenious ways of delivering their services as fewer of the variables associated with the outcomes desired are directly under their control.** The ability to dictate environment and routines could make it more likely that certain outcomes would be achieved or that standards to which others held the provider were met. The successful provider now will have to work more in concert with their client and others, negotiating where they once dictated, in order to make the achievement of outcomes more likely. Fundamentally, it becomes the provider's responsibility to fit in.

• **Providers will have to address a host of issues related to the nuts and bolts of providing services in someone else's home.** These issues might relate to service particulars where myriad seemingly inconsequential details such as meal breaks or personal telephone calls will paralyze the provider who has not anticipated them. They might deal with personnel issues that emerge as clients demand more say about just who provides the services they receive. These might have to do with issues of privacy as a provider may acquire knowledge about activities that they may legally or ethically be required to disclose. Or they might have to do with any of a multitude of other issues. Successful agencies will need to anticipate these kinds of issues, negotiate and develop positions on them, and communicate them to their customers.

• **Providers will have to seek out and embrace contemporary management practices as their organizations come to have more in common with mainstream business.** Our organizations will need to behave more like mainstream business because our customers, once empowered, will be behaving more like mainstream consumers. Many will object to the notion that social service agencies need to operate as business organizations, as if the concept of business management is somehow incompatible with a client orientation. Yet, these same people want the things that good management brings to an organization, things like effective and efficient use of resources and matching of

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Resources for Financing Community Housing

The development of affordable housing for persons with disabilities can be financed through various federal, state, and local sources. In this article a number of the most useful sources are briefly described. It should be noted that in many instances, it is necessary for individual or group project sponsors to combine funding from several sources to produce a viable financing package. These summaries are not intended to be exhaustive of the many financing options available, nor do they provide the many details regarding each option. On the other hand, they should make clear that there are many options and opportunities to secure affordable, culturally typical and well-integrated housing for people with disabilities. Selecting and utilizing these and other options often epitomizes the concept of "creative financing." But no individual or group needs to go it alone. Information sources are provided with each program summary. In addition, in many, if not most communities there are real estate and development professionals who are already knowledgeable about these options.

Major Federal Sources

■ Section 202 Direct Loan Program.

The Section 202 Direct Loan Program is the standard financing mechanism provided by the federal government for subsidized housing for persons with disabilities. Section 202 provides 100 percent direct mortgage loans and rent subsidy for residents. It provides funding for the development of apartment complexes referred to as independent living complexes (ILCs) of up to 24 units on one site, we well as for group homes of up to 15 residents. Section 202 targets very low-income households and individuals whose incomes do not exceed 50 percent of area median income, although some units may be made available to those with incomes between 50 and 80 percent of area median.

Eligible sponsors. Sponsorship of Section 202 housing is limited to non-profit organizations. A separate ownership entity known as "a borrower corporation" must be formed to develop and operate each project.

Program description. Section 202 can be used to finance multifamily rental and limited equity cooperative housing and group homes. The program may be used for new construction of ILCs, acquisition with or without substantial rehabilitation of existing properties for group homes, and new construction of group homes. Prospective sponsors apply directly to U.S. Department of Housing and Urban Development (HUD). Approved projects receive direct mortgage loans and operating subsidies.

Information sources. HUD provides application packages to prospective sponsors.

■ Rental Rehabilitation Program.

The Rental Rehabilitation Program (RRP) of HUD provides grants to rehabilitate existing rental units and provides rental assistance to low-income households. Eligible low-income tenants must have incomes that are at or below 80 percent of area median income. State and local governments design and operate programs tailored to their needs. RRP assistance is limited to low-income neighborhoods in which rents can be expected to remain affordable to low-income households over time.

Eligible sponsors. Private owners of primarily residential rental properties.

Program description. RRP provides a formula allocation of grant funds to state and local governments to make rehabilitation of rental properties financially feasible. Direct allocations go to states, to cities with populations over 50,000, and to urban counties that receive at least a minimum allocation established by HUD. State programs cover areas under 50,000 population and cities over 50,00 population that do not receive the minimum allocation. Grant funds may be used only to correct substandard conditions, make essential improvements, and repair major systems in danger of failure. In addition, 70 to 100 percent of each grantee's funds must be spent on rehabilitation of properties occupied by lower-income families over time. Rehabilitation subsidies are generally limited to 50 percent of rehabilitation costs.

Information sources. Local housing and community development agencies can provide project sponsors with application guidelines and information on funding cycles.

■ Permanent Housing for Handicapped Homeless Persons.

The Permanent Housing Program is part of the Supportive Housing Program, authorized by the Stewart B. McKinney Act. It provides federal matching funds for the acquisition and rehabilitation of a supportive living home for up to eight individuals with disabilities, or a building with up to eight housing units for persons with disabilities and their families who are either homeless, at risk of becoming homeless or who have been residents of transitional housing under the Transitional Housing Program and are eligible to be served under the program. Priority is given to persons with mental illness. Loan funds are available for acquisition and rehabilitation of housing, and

grants are available for moderate rehabilitation and operating costs.

Eligible sponsors. Public housing authorities and non-profit sponsors must operate the home and provide or coordinate support services for residents.

Program Description. The Permanent Housing Program provides four types of assistance: 1) Interest free advances up to the lesser of $200,000 or 50 percent of the cost of acquisition and/or rehabilitation of an existing property; 2) Grants for the lesser of $200,000 (or up to $400,000 in areas with high costs) or 50 percent of the cost of moderate rehabilitation of an existing structure; 3) Technical assistance in connection with the awards above; and 4) Grants for operating costs, not to exceed 50 percent of costs in the first year, and 25 percent in the second year, including costs of support services.

States must apply for funds from HUD to pay for 50 percent of the cost of projects. The other 50 percent must be non-federal funds; these could include state agency funds from a human services agency, a direct appropriation through the state legislature, the value of a building or other materials to be used, or the non-federal portion of funds from other federal programs. Only supportive living environments that provide housing for up to eight individuals with disabilities and their families can be funded under the Permanent Housing Program, although certain waivers are possible for projects that will still achieve community living goals.

Information sources. Contact the local HUD field office for program application guidelines. Prospective project sponsors submit applications to a designated state housing finance agency.

■ Community Development Block Grants.

Community Development Block Grants (CDBG) are made by HUD to local communities for use in financing projects that foster development of viable urban communities. Local community development departments generally administer CDBG funds and make awards. Funds can be used to make outright grants, but are frequently awarded as below-market interest rate loans. At least 51 percent of CDBG funds are to be targeted to projects benefiting low- and moderate-income persons. As long as a project provides documented benefits to low- and moderate-income households, there are no formal requirements limiting eligible residents.

Eligible sponsors. Local community development agencies award CDBG funds to non-profit organizations. Private sector builders/developers may receive CDBG funds if channeled through a non-profit organization.

Program description. Within broad parameters established by HUD, local jurisdictions develop their own guidelines for projects eligible for CDBG funding. Most communities attempt to leverage CDBG benefits by using them to provide a portion rather than all the financing needed for a project. Typical uses of funds include low-interest second mortgages and low-interest construction financing. Funds can be used for building acquisition, relocation, demolition, rehabilitation, and in some cases, new construction. CDBG funding is frequently used by project sponsors as "gap financing" that provides the final increment needed to complete a financing package.

Information sources. Local housing and community development agencies can provide project sponsors with application guidelines and funding cycle information.

■ Rental Assistance - Housing Vouchers and Section 8 Certificates.

Housing vouchers and Section 8 certificates provide assistance to low- and moderate-income tenants to reduce their rental payments. Rental assistance is targeted to individuals with less than 80 percent of the area median income adjusted for family size. Tenants apply directly for vouchers and existing Section 8 certificates.

Eligible sponsors. Vouchers and Section 8 certificates are administered by local housing agencies. Non-profit groups may enter into arrangements with their local housing agencies to obtain vouchers or Section 8 certificates on behalf of eligible individuals or families.

Program description. Vouchers and Section 8 certificates provide rental assistance to low-income tenants in much the same way. The primary difference lies in how the amount of assistance is computed and the options available to the tenants in obtaining housing.

Section 8 certificates provide assistance to cover the difference between 30 percent of a tenant's adjusted income and the fair market rate rent for a unit. Housing vouchers, on the other hand, provide a predetermined subsidy based on prevailing local rental rates. Tenants can then shop for housing at whatever rent they are wiling to pay. Vouchers or certificates may be used as subsidies for residency in a supportive living environment. Several programs around the country have used vouchers and Section 8 certificates as an alternative to housing development, choosing instead to assist individuals with disabilities in obtaining rental assistance and providing whatever supports are needed in the home chosen by the individual or individuals.

Information sources. Local public housing authorities state housing finance agencies or the HUD regional office can provide application information.

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■ Low-Income Housing Tax Credit.

The low-income housing tax credit is a mechanism for raising private equity through limited partnerships. The low-income housing tax credit provides a reduction in tax liability for 10 years to owners/investors in low-income rental housing. The property must be held as low-income housing for at least 15 years. The amount of the tax credit is calculated on the basis of acquisition and/or development costs and on the number of qualified low rent units. Projects may include single-family units, small and large apartment buildings, and limited equity housing cooperatives. Low-income occupancy restrictions require projects to include either 20 percent of units for persons or households with incomes at 50 percent or less of area median, or 40 percent of units for persons or households with incomes at 60 percent or less of area median.

Eligible sponsors. Projects sponsored by either builders, developers, or non-profit developers are eligible to apply for tax credit allocations. Ten percent of each state's allocation must be allotted to non-profit developers.

Program Description. Each state has a cap or limit on total tax credit allocations calculated on a per capita formula basis. Tax credits are allocated by the state housing credit agency to specific rental projects based on applications. The amount of the tax credit is calculated at approximatley nine percent of eligible project costs annually for 10 years for new construction and substantial rehabilitation. The tax credit is reduced to approximately four percent annually for costs of property acquisition, moderate rehabilitation, projects financed with federal funds, and projects financed with tax-exempt bonds.

Information sources. State and local housing finance agencies can provide project sponsors with tax credit application procedures.

Major State/Local Sources

■ Tax-Exempt Bonds for Multi-Family Housing.

Tax exempt bonds are issued by local or state housing finance and economic development agencies to provide below-market rate financing to build or acquire and substantially renovate multifamily housing. Because the interest paid to bond-holders is not taxable, issuing jurisdictions pay a lower rate of interest. The savings from the reduced interest payments are passed on to the developer, ultimately resulting in lower rent payments. Tax-exempt bonds are intended to provide affordable housing for the general market. Multifamily housing financed through tax-exempt bonds targets low-income tenants. Projects must have either 20 percent of units reserved for persons or households with incomes at or below 50 percent of area median adjusted for family size, or 40 percent of units reserved for households with incomes at or below 60 percent of area median adjusted for family size. In some instances, a portion of a jurisdiction's bond authority has been reserved for projects to house people with disabilities. With public purpose bonds, and non-profit private activity bonds, the bond issuer determines the rent levels, unit mix and project locations, but the 20/50 and 40/60 income restrictions do not apply.

Eligible sponsors. There are two types of tax-exempt bonds for multifamily housing: governmental bonds and private activity bonds. Governmental, or public-purpose, bonds have no volume ceiling, but these securities can only be used for projects under government ownership. Bonds issued to finance rental housing projects undertaken by private developers, called multifamily industrial development bonds (IDBs), are classified as private activity bonds. Private activity bonds are subject to a state-by-state annual per capita limit, except for bonds used to finance projects sponsored by non-profit organizations.

Program description. The federal government tax code allows local and state housing finance agencies to issue tax-exempt bonds to develop affordable housing. Tax-exempt bonds provide financing at an interest rate typically 1.5 to 2 percent below the market rate. Tax-exempt financing can be used to fund new construction, substantial and moderate rehabilitation for five or more units in multifamily buildings, and supportive living environments. Each housing finance agency develops application procedures for project financing. Most receive proposals on an ongoing basis. To achieve affordability, bond financing is frequently combined with other subsidies.

Information sources. Local or state housing finance agencies can provide sponsors with application information.

■ Tax-Exempt Bonds for Single-Family Mortgages.

State and local housing finance agencies are authorized by the federal government to issue tax-exempt bonds to provide below-market interest rates on single-family home mortgages for first-time buyers of single-family, owner-occupied homes. A borrower's income can not exceed 115 percent of the higher of state or area median income. The home price must not exceed 90 percent of the average area purchase price. Additional latitude on income and purchase price limits is permitted in targeted areas. Mortgage Revenue Bonds (MRBs) are classified as private activity bonds and are subject to a state-by-state annual per capita ceiling.

Eligible sponsors. MRBs provide purchase financing for homes built by private non-profit or for-profit developers. Allocation of funds varies by state, but is usually done through lenders. Some states set aside portions of MRB issues for new construction. Non-profit developers may also apply for reservations of mortgage loan funds to assist income-eligible purchasers of units developed by the non-profit.

Program description. Single-family mortgage tax-exempt bonds are issued by housing finance agencies. The proceeds are generally allocated through qualified lenders who are authorized by the issuing agency to process loan applications. Because of the federally imposed "cap" on the issuance of tax-exempt, single-family mortgage bonds, which typically provide for mortgages 1.5 to 2 percent below the market rate, the number of applications exceeds the available resources. Lotteries are frequently used to select mortgage recipients.

The Mortgage Credit Certificates (MCCs) program is a companion to the mortgage revenue bond program. MCCs allow qualified home buyers to reduce their federal tax liability by a percentage of their home mortgage interest payments. The certificates are issued by state and local housing finance agencies (HFAs) through mortgage lending institutions.

Information sources. Contact local or state housing finance agencies for information on application procedures and anticipated funding cycles.

■ Housing Trust Funds.

Housing trust funds are financed by a dedicated revenue source such as development fees or a surtax on commercial real estate transfers earmarked for affordable housing development. Trust funds are typically established and operated by state or local housing finance agencies and primarily address housing affordability without regard to the disability of housing occupants. A few jurisdictions have designated a portion of their trust funds for housing for persons with disabilities. The housing trust fund concept can lend itself to providing low-interest rate financing for accessibility improvements to individual rental units as authorized by Fair Housing Act Amendments of 1988. Either a portion of an existing housing trust fund might be allocated for such loans, or a separate trust fund could be established for this purpose. Eligible occupants of units developed with housing trust fund loans are generally restricted only on the basis of income. In some areas, households must have incomes below 80 percent of the area median. Other jurisdictions have sliding scale interest rates where developers receive deeper interest subsidies for units affordable to low-income households (e.g., 3 percent loans) and slightly higher rates (e.g., 6 percent) for units affordable to moderate income households.

Eligible sponsors. In most jurisdictions, housing trust fund loans can be applied for by non-profit or for-profit developers who agree to develop units meeting local affordability criteria.

Program description. Housing trust funds provide developers of multifamily or single-family units with below-market interest rate loans in return for the production of units targeted to low- and moderate-income renters and home buyers. Jurisdictions structure housing trust fund subsidies in various ways. Funds may provide below-market rate construction and permanent mortgage loans or second mortgages for affordable multifamily units. Low-interest second mortgages may be used to subsidize a portion of the units in an otherwise market-rate apartment development. In the case of single-family development, housing trust funds may provide "soft" second mortgages (i.e., very low interest rates, interest-only payments, or no repayment due until the unit is sold). In some cases, resale prices of single-family units are subject to restrictions to ensure that the unit remains part of the affordable housing stock.

Information sources. State housing finance agencies and local housing and community development agencies can provide project sponsors with information on housing trust funds in their jurisdictions (see also David Rosen, *Housing Trust Funds*, American Planning Association, 1987. (Planning Advisory Service Report Number 406).

There are a number of other state and local funding programs available that provide resources for financing community housing for individuals with disabilities. Information on those options can be obtained through state housing finance agencies, local housing and community development departments, local independent living centers, and state and local departments of human services.

Excerpted from ***Financing Housing for People with Disabilities: The Financing Mechanisms****, by the National Association of Home Builders, National Association of Home Builders National Research Center, and Association for Retarded Citizens of the United States, May 1989.*

Editors' note: We wish to thank Bill Mitchell for his assistance in producing this article and the article "Organizing to Develop Housing" on page 8 of this issue of IMPACT. Bill is the Director of the Housing Technical Assistance Project of the Association for Retarded Citizens -U.S. He may be reached at ARC-US, 1522 K Street NW, Suite 516, Washington, DC 20005.

Housing Ownership Options:Pros and Cons

Listed below is a brief summary of some of the advantages and disadvantages of different consumer controlled housing options.

Advantages	*Disadvantages*
Tenant Owned	
• Normalized lifestyle. • Pride of ownership. • Control over living environment. • Equity.	• Possible difficulty with down-payment. • Potential for becoming overwhelmed with responsibilities of ownership.
Parent Owned	
• Promotes active parent role in care of son/daughter. • Parents have greater potential for making down payment. • Possible tax credits to parents investing in property to benefit son/daughter.	• Potential tax liability in future. • Less control by consumer. • Extra work for parents.
Trust Owned (ownership assigned to "living trust," set up by parents)	
• Parents can set aside and protect a portion of their assets for benefit of son/daughter while maintaining eligibility for government programs.	• Laws affecting trusts may change over time. • Legal expenses of setting up and maintaining trust.
Corporation Owned (parents and others set up corporation to purchase, own and maintain housing)	
• Potentially the most durable option. • Owners can limit their liability.	• Loss of parent control to board of directors. • Red tape and legal expenses of setting up corporation.
Partnerships (parents combine resources with other parents to purchase dwelling)	
• Combined resources yield greater purchasing power.	• Upon exit of a partner, remaining partners may be left with substantially increased financial burden.
Shared Equity (tenant makes purchase with another and gradually buys out the other party)	
• Greater purchasing power. • Allows full responsibility of ownership to be achieved gradually.	• Control of property by resident somewhat diminished.

Adapted from ***New Housing Options for People with Mental Retardation or Other Related Conditions: A Guidebook****, by the Minnesota Department of Human Services, Mental Retardation Division, and ARC-Minnesota.*

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The ARC's policy supports the phasing out of those services, activities, and environments which:

- Inappropriately remove children and adults from their homes and neighborhoods.
- Require that persons with disabilities live under circumstances that would not be considered acceptable for persons within the same age range when they are not disabled.
- Prevent or hinder normalized social support networks, family systems, peer relationships and friendships.

During the phasing-out process, quality care must be assured for persons residing in such living environments.

Taken from position statement of Association for Retarded Citizens - U.S., 2501 Avenue J, Arlington, TX 76011.

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services to consumer needs. While rejecting the concept of a marketplace they want all the consumer benefits of an effective one. The onus will be on us, as with business in general, to use the resources available in a way that best meets consumers' expectations.

As persons with developmental disabilities gain more control over their homes and other aspects of their lives, the environment in which residential service providers work will be fundamentally altered. Those providers that adapt to meet changing expectations will likely see new opportunities at their doorstep while others will struggle.

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Resources

Listed below are printed resources providing further information on consumer controlled housing.

Manuals and Reports

• **"In Search of Housing."** (1987). By Francis L. Randolph, Bob Laux, and Paul Carling. This monograph describes the advantages and financial mechanisms for using existing traditional real estate options, and public and private financing opportunities, to create affordable consumer controlled integrated housing for people in need of support. The bulk of the monograph is focused on a wide variety of real estate and financing strategies available to acquire housing. Available from the Center for Change Through Housing and Community Support, Department of Psychology, John Dewey Hall, University of Vermont, Burlington, VT 05405.

• **"Financing Housing for People with Disabilities: The Financing Mechanisms."** (1989). By the National Association of Home Builders Research Center and the Association for Retarded Ctiizens - U.S. This monograph presents detailed information on many financing mechanisms available for developing affordable housing for people in need of support. The report includes descriptions of federal, state and private programs and general mechanisms for financing. It describes basic models of housing development. It also contains worksheets to assist sponsors in estimating costs, revenues, and expenses, as well as sources and uses of funds. Available from the Housing Technical Assistance Project, ARC-US, Suite 516, 1522 K Street NW, Washington, DC 20005, (202) 785-3388. Or from HTAP, NAHB Research Center, 400 Prince George's Blvd., Upper Marlboro, MD 20772-8731, (301) 249-4000.

• **"Financing Housing for People with Disabilites: The Development Process."** (1989). By the National Association of Home Builders Research Center and the Association for Retarded Citizens - U.S. This report outlines on a step-by-step basis the stages of a housing development project. Stages discussed include organizing to develop a project, needs assessment activities and organizational development, assembling a developmental team, evaluating the market, selecting a housing model, developing a financial plan, and securing housing. Available from the Housing Technical Assistance Project, ARC - US, Suite 516, 1522 K Street NW, Washington, DC 20005, (202) 785-3388. Or from HTAP, NAHB Research Center, 400 Prince George's Blvd., Upper Marlboro, MN 20772-8731, (301) 249-4000.

• **"New Housing Options for People with Mental Retardation or Other Related Conditions: A Guidebook."** (1988). By the Minnesota Department of Human Services and the Association for Retarded Citizens - Minnesota. This guidebook presents an introductory overview of the topic of consumer owned housing. In addition to a description of philosophic principles underlying the move toward consumer-owned housing, it outlines some of the basic steps to developing housing. It also contains four brief case studies of successful consumer owned housing projects. Available from ARC - Minnesota, 3225 Lyndale Avenue South, Minneapolis, MN 55408, (612) 827-5641.

• **"Moving Into the 1990s: A Policy Anaylsis of Community Living for Adults with Developmental Disabilities in South Dakota."** (September 1989). By Julie Ann Racino, Susan O'Connor, Bonnie Shoultz, Steven J. Taylor, and Pamela Walker. This volume is the report of technical assistance observations and activities by the Center for Human Policy for the State of South Dakota. It focuses on the modification of the existing services system as well as makes recommendations for the development of new services in the 1990s. Of particular interest is Part II of the volume, entitled "Housing/Support Services Approach to Community Living." In it the basic premises of consumer controlled housing are laid out. An excellent listing of resources is provided in the report. Available from the Center on Human Policy, 200 Huntingron Hall, Syracuse University , Syracuse, NY 13244-2340, (315) 443-3851.

Periodicals

• **"New Ways" magazine**. (Summer 1989). This issue of New Ways contains an eight page feature on parent owned housing, including the personal experiences of several families, and some of the legal and financial considerations. Available from New Ways, P.O. Box 5072, Evanston, IL 60204, (312) 869-7210.

• **"Community Living for Adults"**. (November 1989). By the Center on Human Policy, Syracuse University. This 16-page newsletter describes the experiences of persons with disabilities who control their own lives in their own homes. It identifies and describes agencies providing supports to individuals with severe disabilities so that they can live in their own homes. Principles governing and issues facing the consumer controlled housing movement are also identified. Available from the Center on Human Policy, 200 Huntington Hall, Syracuse University, Syracuse, NY 13244-2340, (315) 443-3851.

Lockwoods, continued from page 7

at the house with the four housemates. Two staff are at the house whenever the four women residents are home. At times when the Lockwood sisters and their roommates are at work, the staff are out at other jobs.

Just like any other home, each person has their own responsibilities and their own interests. Each housemate, with assistance from the staff, contributes to the housecleaning duties, meal preparation, grocery shopping, and meal cleanup. Currently all four residents work at a developmental achievement center; Audrey and Bob are in the process of moving their daughters to another center location because they'd like them to be able to interact with other people besides their roommates. Out of the home leisure activities include attending a weekly *I AM HIS* club at church. Other leisure activities are in-home with roommates or alone; Audrey and Bob would like their daughters to increase their social outings through involvement in evening group activities at least three times a month. This is a goal they continue to work on.

The arrangement has not been without problems. The Lockwoods are not completely satisfied with the management company. There seems to be a breakdown in communication from the company to the parents, leaving Audrey and Bob uninformed about some changes. And there is some dispute over home maintenance that isn't being adequately handled by the company. Other management firms are being considered, but there is a problem in common with them all: the companies want the Lockwoods to hire a husband/wife couple to live in the home as a solution to the maintenance problem (the assumption being that a man is needed to maintain the yard and house). Audrey and Bob don't want such a couple living there, in part, because that couple would take on the role of parent figures with their daughters. They want Stacy and Druanne to continue to live on their own with female peers, not second parents. If a satisfactory arrangement with a management company can't be made, Audrey and Bob will consider moving back into the home. This option would, however, reduce their daughter's independence and it is viewed as a last resort.

Whatever form the household ultimately takes on, Bob and Audrey remain committed to their daughters having a home of their own and living their lives in the community.

The interviews for this article were conducted by Christine Stehly, Institute on Community Integration, University of Minnesota. Photos by Christine Stehly.

Parent, continued from page 7

• **Homestead exemption or tax break**: Does the son/daughter get this or the parents?

• **Proximity**: Although most parents [I've spoken with]liked living near their child's home, some parents wanted enough distance between the houses to ensure that their son or daughter couldn't visit them all the time.

• **Choices**: Who chooses the furnishings or decorating for the home's interior/exterior?

• **Routine maintenance**: For plumbing problems and the like, amounts large enough to cover estimated maintenance and repair usually are figured in the monthly payment the provider leasing the house makes to the parents. The parents then are responsible for getting the work done. Problems often arise over another type of maintenance: who mows the lawn, shovels snow, and cleans the house? What happens if the jobs don't get done?

• **Training of staff**: Because salaries may be low, staff members often are young people who have never maintained a home themselves. They may not know how to cook. They may never have been taught how to do laundry for four or five people. They may never have been taught how to set some kind of schedule to keep the house clean or how to buy a rake that will not fall apart. Training staff members in these types of skills needs to be considered.

*By Edward Skarnulis, researcher with the Minnesota Department of Human Services, 1313 5th Street SE, Suite 315, Minneapolis, MN 55414. Taken from "Thorny Issues", **New Ways** magazine (Summer 1989), copyright 1989, all rights reserved. Reprinted with permission.*

Home, continued from page 1

specific type of funding, such as Medicaid's ICF/MR program, or HUD's Section 202 program with Section 8 Rental Certificates, undeniably dictates the lifestyle to follow. In an effort to obtain what is perceived to be long-term, stable financial assistance, human service professionals sometimes compromise the values inherent in their own lifetsyles. Apparently whatever can be determined as cost effective or within a specific unit rate structure can also be determined as acceptable as a lifestyle for persons with disabilities.

It's hard to argue about cost effectiveness with some people. Some may never appreciate the substantial benefit and savings of a consumer empowered and controlled community. Still others may never accept the benefits of true integration where friends and neighbors help each other, and the community maintains the capacity to accept all of its citizens as equals. The doubters will be stuck on continuums, cost containment, unit rate formulas, wage parities, "the regulations made me do it", and "we tried that once and it didn't work."

Over the past ten years or so many of us charged with the expansion of housing options and community support services for people with disabilities have realized that nothing -- not cost, disability, support needs, community opposition, or legislation -- should prevent a person from having a place to call home. The reality of financial constraints placed on all of us suggests that many of us may need a roommate, friend, or family member to share a condo, townhouse, single family home, or apartment. To assume that because a person has a substantial disability those options are not practical or possible, is simply wrong.

It is widely recognized that most people with significant disabilities need community support. The challenge to the system, however, is to provide those services wherever the person lives. During a recent trip I noticed a section of a local phone book that identified services for seniors including things like meals, transportation, legal services, pharmacists, visiting nurses, financial services, and bankers. I was amazed at the array of options available. The reality is, those are exactly the services many people with disabilities require. Why are they only available for seniors? Most probably it has to do with the value a community places on its various citizens.

Integration and inclusion will be achieved when society values its citizens with disabilities as it does others. When people with disabilities live in homes of their choice, with people they select, and have support available to meet their needs, inclusion will be at hand. When our federal, state and local governments value people more than defense, natural resources, private interest groups, or professional provider lobbyists, integration will be within grasp. When citizens with disabilities have a place to hang their hats, enjoy a crackling fire, gather with family and friends... a place of their own... they will be home.

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Organizing, continued from page 9

frustrated by lack of overall development expertise, limited familiarity with the regulatory framework that governs development, limited knowledge of financial packaging, and a failure to obtain appropriate technical assistance. Housing developers, on the other hand, typically have less firsthand knowledge of the housing needs of people with disabilities or the market opportunity they represent. By joining forces, consumers, advocacy and other non-profit organizations, and experienced housing developers can bring their respective skills and contacts to the development process and devise successful strategies that increase the supply of housing for people with disabilities.

The motivations and rewards for forging these links vary among advocacy groups, housing developers, and consumers. Advocacy groups are committed to serving the various needs, including the need for shelter, of their constituencies. Their overall goal is to improve the quality of life of people with disabilities, to promote independent living, and to create opportunities for integrating people with disabilities into the community. Their involvement with housing as sponsors helps fulfill this mission. A building company may decide to participate in a particular federal, state, or local funding program that encourages the production of affordable, accessible housing as a means of business diversification into an untapped market niche. In some instances, a particular builder or remodeler takes part because of personal experience with the disability community or as a community service. Real estate professionals are likely to participate in obtaining existing housing because of the sales commissions.

People with disabilities are interested in improving access to housing for themselves and other persons with disabilities. As a group they are working to ensure that all citizens have the right to live and participate in the community with the maximum possible control over their own lives.

When groups seemingly as disparate as non-profit advocacy groups, consumers, and builders join forces, local government officials are likely to pay attention to the effort. This combined strength may be a force in securing regulatory, tax, and other incentives to accelerate the development approval process and/or otherwise enhance housing affordability. At the least, the joint involvement of these groups vests the issue of housing for people with disabilities with greater visibility than if any group were acting alone.

Excerpted from ***Financing Housing for People with Disabilities: The Development Process,*** *by the National Association of Home Builders, National Association of Home Builders National Research Center, and Association for Retarded Citizens of the United States, May 1989.*

IMPACT: Feature Issue on Consumer Controlled Housing for Persons with Developmental Disabilities

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- *Financing alternatives.*
- *Challenges and guidelines for service providers.*
- *Considerations for housing sponsors.*
- *Areas of concern for parents.*
- *One family's experiences.*
- *Replacing the continuum model of housing.*
- *Print resources for further information.*

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Spring 1990

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Issue Editors: Edward Skarnulis
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The mission of the Center and Institute is to apply their resources to improve the quality and community orientation of professional services and social supports available to persons with developmental disabilities and their families. Efforts are directed at facilitating the independence of citizens with developmental disabilities and their social integration into the mainstream of community life. Inquiries about the Institute, Center, or IMPACT can be directed to:

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